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Applied behavior analysis programs for autism:  
Sibling psychosocial adjustment during and following intervention use

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**Running Head:** APPLIED BEHAVIOR ANALYSIS AND SIBLINGS

## Abstract

Psychosocial adjustment in siblings of children with autism whose families were using a home-based, applied behavior analysis (ABA) program was compared to that of siblings in families who were not using any intensive autism intervention. Data gathered from parents, siblings and teachers indicated that siblings in ABA families experienced neither significant drawbacks nor benefits in terms of their behavioral adjustment, sibling relationship quality and self-concept compared to control group siblings, either during or following intervention use. Parents and siblings perceived improvements in sibling interaction since the outset of ABA, with parents somewhat more positive in their views than were siblings. Social support was associated with better sibling outcomes in all groups. Implications for supporting families using ABA are considered.

**Keywords:** applied behavior analysis, autism spectrum condition, early intensive behavioral intervention, family, home-based intervention, siblings

**Abbreviations:** ABA: applied behavior analysis; CA: chronological age; GARS: Gilliam Autism Rating Scale; PSI: Parenting Stress Index; SIB: Sibling Inventory of Behavior; SDQ: Strengths and Difficulties Questionnaire

## Applied behavior analysis programs for autism:

### Sibling psychosocial adjustment during and following intervention use

The impact of children with autism on the family has come to be better understood over the past 20 to 30 years. Family systems theory, emphasizing the reciprocal influences of family members on each other (Cox & Paley, 1997), predicts that the psychosocial adjustment of both parents and siblings is likely to be affected, either directly or indirectly, by the presence of a child with autism.

It is now relatively well established that some parents of children with autism, particularly mothers, report higher levels of parenting stress than mothers of typically developing children or children with other disabilities (e.g. Fisman et al., 1996; Weiss, 2002). In contrast, the effects on sibling adjustment are rather less clear, with the results of studies to date largely equivocal. Some studies have found greater behavior difficulties, higher levels of internalizing problems (e.g. depression and anxiety), and lower levels of pro-social behavior in comparison to control groups of siblings of typically developing children (Fisman et al., 1996; Hastings, 2003a; Verté, Roeyers, & Buysse, 2003). Other studies have reported similar adjustment levels in comparison to control siblings in terms of behavior difficulties, internalizing problems, social competence, self-concept and quality of sibling relationship (Bågenholm & Gillberg, 1991; Kaminsky & Dewey, 2002; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). Others yet have reported higher levels of self-reported social competence and self-concept, and higher levels of acceptance and warmth in the sibling relationship in comparison to controls (Fisman et al., 1996; Macks & Reeve, 2007; Roeyers & Mycke, 1995; Verté et al., 2003).

Differences in participant demographics, recruitment methods, formation of control groups, data collection methods and measurement tools, as well as the small sample sizes in

some studies make it difficult to draw firm conclusions from research to date; this is also true of research with siblings of children with disabilities more broadly (Hodapp, Glidden, & Kaiser, 2005). What is clear, though, is that for some siblings the experience of having a child with a developmental disability in the family is a relatively positive one, and for others it may - at least at some points in time - be problematic (Stoneman, 1998).

Accounting for this variation in sibling outcome has become a key theoretical and clinical goal for autism researchers (Hastings, 2003a). Demographic factors alone - such as sibling age and family size - seem to have limited explanatory power. Studies into these factors have shown relatively limited and, in some cases, contradictory findings. Some studies, for example have found that larger family size is associated with better outcomes for siblings (e.g. Kaminsky & Dewey, 2002), whereas other have found no such association (e.g. Mates, 1990). In contrast, psychological variables - such as symptomatology of the child with autism, parental stress levels, and availability of social support - which link more closely with theoretical notions of the family as an integrated, dynamic system, seem to have greater potential to explain individual differences in sibling adjustment (Fisman et al., 1996; Fisman, Wolf, Ellison, Gillis & Freeman, 2000; Hastings 2003b; Kaminsky & Dewey, 2002; Pilowsky et al., 2004; Rivers & Stoneman, 2003).

Although this field is gradually beginning to unravel the psychological variables which either exacerbate or protect against sibling adjustment difficulties, the role of the broader family environment has often been neglected. In particular, the choices that families make regarding interventions for their child with autism may have a considerable effect on family life as a whole. Home-based interventions in particular are likely to have substantial impact, both positive and negative, on the family's time, finances, stress and quality of life. As yet, though, such variables have been seldom considered within family research. It was this concern that drove the present study. It specifically sought to explore the extent to which the

use of a home-based behavioral intervention for the child with autism impacts on sibling psychosocial adjustment, and how any such impact is mediated by other psychological variables, such as parental stress or social support networks.

The study focuses on families using applied behavior analysis (ABA), an intensive home-based intervention for autism. For many years, research into this approach focused almost exclusively on efficacy for the child with autism. However, following a move away from clinic-based intervention programs to those in which parents take on a central role, a more family-centered perspective has also gradually been adopted in efficacy research. Interventions such as ABA are now beginning to be considered more often in terms of the outcome across the whole family (e.g. Hastings & Johnson, 2001; Remington et al., 2007; Schwichtenberg & Poehlmann, 2007).

Adopting a family-systems perspective, there is reason to predict that ABA would have a positive impact on sibling psychosocial adjustment, as a result of the direct benefits it has for some children with autism. For example, early intensive behavioral interventions based on ABA have been shown to enhance IQ, communication, positive social behavior and adaptive behavior in some children with autism (e.g. Eldevik et al., 2010; Reichow, 2011; Remington et al., 2007). This in turn is likely to ease interactions and relationships within the family, including those with siblings.

Another factor that might contribute to positive outcomes for siblings relates to the finding that parents involved in ABA tend not to report increased stress levels, and in some cases even report slightly decreased levels. For example, Smith, Groen and Wynn (2000) found that mothers of 15 children with autism or pervasive developmental disorder involved in intensive early intervention, from when the child was around 3 years of age for upwards of 2 years, reported slightly decreased stress during the intervention. Remington et al. (2007) compared well-being in parents of 23 children involved in an early intensive behavioral

intervention with parents of 21 control group children. The mothers did not report significantly higher levels of stress, anxiety or depression compared to the control group when assessed at follow-up points 12 and 24 months later. Fathers of children in the intervention group showed an increase in depression, but no differences from the control groups on the other measures. Other studies have similarly shown no increases or even slight decreases in maternal stress associated with intervention involvement (e.g. Hastings & Johnson, 2001; Birnbrauer & Leach, 1993). Some of these studies were small-scale, and findings may be dependent on the extent and nature of parents' intervention involvement (e.g. Schwichtenberg & Poehlmann, 2007). However, they do suggest that involvement in behavioral interventions is not necessarily a predominantly negative experience for parents, and in the longer-term may even slightly reduce stress levels for some families. Given that parental stress and sibling adjustment have been shown to be related in children with developmental disabilities (e.g. Fisman et al., 2000), it is possible that siblings will benefit from these somewhat positive parental outcomes. Depending on how the program is implemented there may also be other benefits to siblings, for example, uninterrupted time with parents while other therapists work with the child with autism.

Only a few studies to date have explored in detail the psychosocial adjustment in siblings of children with autism involved in ABA programs. Hastings (2003b) looked at 78 families who had been using ABA for an average of 14 months. The children with autism had a mean age of 5 years, and in the majority of cases the mothers reported on an older sibling. Most mothers were involved as therapists, providing an average of around 7 hours of therapy per week, with additional hours provided by the partner and other therapists. All mothers were asked to rate the behavioral adjustment of the sibling using the Strength and Difficulties Questionnaire (SDQ; Goodman, 1997). These ratings indicated evidence of lower levels of

sibling adjustment difficulties on several of the SDQ domains in comparison to normative data.

Although these findings are encouraging, Hastings rightly urges a cautious interpretation, stating that on the basis of these data it would be premature to conclude that ABA is beneficial for siblings. Effect sizes were small and the normative comparison group was not matched to the study sample in terms of socio-economic status or the presence of a child with a disability in the family. In addition, only one measure of behavioral adjustment was gathered from the mothers, leaving the possibility that sibling adjustment findings may have been different if data from a broader range of measures had been gathered from other informants, including the siblings themselves. This is particularly important since parents' views on sibling adjustment may be affected by their own stress levels and by their perceptions of how successful the intervention is for the child with autism. The effects on siblings in the longer-term, following cessation of the intervention, are also currently unclear.

A second study which explored the experiences of siblings involved in ABA programs from the perspective of their parents was an interview study conducted by Grindle, Kovshoff, Hastings, and Remington (2009). Mothers, and in many cases also fathers, in 27 ABA families with a child with autism and a typically developing sibling participated in interviews. These explored a number of areas including parents' perceptions of the practical benefits and difficulties associated with running the program and its impact on family life. Over three quarters of parents reported benefits to the sibling, including the fact that the sibling enjoyed being involved in therapy sessions and benefited from learning about autism and successful ABA interaction techniques. Over half of the families reported that the relationship between the siblings had improved as a result of ABA, usually because siblings had become more able to play together. A number of parents also felt that their own relationship with the sibling had improved. While there were some negative effects reported



(e.g. around a third of parents reported that the sibling felt that they received less attention and that there were fewer opportunities for outings), again this does suggest that ABA may, in some respects at least, be beneficial for siblings. As the authors note, though, the research did not aim to explore the relationships between variables such as intervention intensity and family outcome. Nor did it focus on the views of the siblings themselves. However, by exploring the perceptions of parents it provides an insight into the experiences of siblings in families using this intensive approach.

The present study aimed to test the hypothesis that home-based ABA programs for children with autism will have beneficial effects on siblings in terms of their psychosocial adjustment and relationship with the child with autism. Specifically, it explored the effects of ABA implementation on siblings both in families currently involved in ABA programs and in families who had used ABA in the past, but were no longer doing so. Data on sibling adjustment were gathered not only from the parents, but also from the siblings and their teachers. Previous research has shown that these different groups of respondents do sometimes differ in their perceptions on sibling adjustment (Cuskelly & Gunn, 2003; Fisman et al., 1996), and it was therefore important to gather data from all three sources.

The ABA families were compared to a matched control group of families who also had a child on the autism spectrum but were not using any intensive interventions. Questionnaire data were gathered on a wider range of psychosocial domains than has previously been examined, including behavioral adjustment, sibling relationship quality, and self-concept. In order to explain any variation in levels of sibling adjustment across the families, the study also sought to explore the extent to which psychological and ABA intervention variables were predictive of sibling adjustment during and following intervention use.

## Method

### *Participants*

One hundred and thirty-two families with a child on the autism spectrum and a typically developing sibling aged 4–16 years participated in this study. Of the 132 families, 45 were currently using ABA ('ABA group'), 26 had used ABA in the past but were no longer doing so ('Post-ABA group'), and 61 control families were not currently using any intensive home-based intervention, nor had done so in the past (although some were using short-term, or non-intensive interventions, such as speech and language therapy). One parent per family completed a questionnaire pack (see below) in relation to one typically developing sibling: either a 9-16 year old sibling if there was one in the family, or if not, the sibling closest in age to the child with autism. In families in which the typically developing sibling was 9-16 years, they were asked whether they would be willing to participate directly by completing a sibling questionnaire pack (typically developing siblings aged 4-8 years old did not participate directly). If both the sibling and the parent agreed, the sibling's class teacher was also contacted and asked to complete a short questionnaire.

Groups were matched on the basis of parent questionnaire data on demographics and on severity of the child's autism, as measured by the Gilliam Autism Ratings Scale (GARS: Gilliam, 1995). From the 61 control families a sub-sample of 45 was matched to the ABA group ('ABA control group') and a sub-sample of 26 was matched to the Post-ABA group ('Post-ABA control group'). As Table 1 shows, groups were closely matched on a wide range of child/family demographic variables. In order to achieve this, there was some overlap between the two control groups, and 23 families served as both ABA and as Post-ABA controls.

[Table 1 about here]

### *Group matching*

*ABA and ABA control groups.* Demographic information on these two groups is given in Table 1. In both groups the majority of parental respondents were mothers (N = 41 (91%) and 43 (96%) out of 45 respectively). In both groups 43 respondents were white British, 1 was Asian or Asian British and 1 was mixed/other ethnicity. In the ABA control group, one family reported on half-siblings and another reported on adopted siblings; in all other families parents reported on full biological siblings. There were no significant group differences in any of the demographic characteristics listed in Table 1, with the exception of school attendance. Of the children with autism who attended school, those in the ABA group were significantly more likely than those in the control group to attend on a part-, rather than a full-time basis ( $\chi^2(1) = 25.30, p < .001$ ).

Forty-four siblings (22 from each group) were old enough to complete questionnaires themselves. The mean age of these siblings was 11.25 (SD = 1.42) years in the ABA group and 12.08 (SD = 1.92) years in the Control group. These sibling groups did not differ significantly in terms of: the age and autism quotient of the child with autism, the presence of intellectual disabilities in the child with autism, or the age and gender of the typically developing sibling. In the remaining 46 families (23 from each group), siblings were not old enough to directly complete questionnaires (4.00 - 8.92 years), but parent and teacher measures were completed.

Teachers for 70% of the siblings (ABA = 30; Control = 33) completed questionnaire measures (see below). The remaining teachers were either non-respondents or were not sent the questionnaire at the request of the family. Families for whom teacher data were provided did not differ from families for whom such data were not provided in terms of: the age and autism quotient of the child with autism, the presence of intellectual disabilities in the child with autism, or the gender of the typically developing sibling. However, siblings were significantly younger in families for whom teacher data were provided ( $t(88) = 2.94, p =$

.004). This perhaps was partly because teenage siblings were somewhat less keen for their teachers to be involved (indicated during initial phonecalls to participating families), and partly because the secondary school return-rate was lower than that of primary schools. Comparison of the ABA and the Control families with a linked teacher participant revealed no significant between-group differences in any of the demographic variables listed above, with the exception that the autism quotient of the child with autism was higher in the Control families ( $t(61) = -2.50, p = .015$ ).

Respondents completed a demographic questionnaire (see below). For the ABA families this included questions about their intervention. Table 2 provides characteristics of intervention use in the 45 ABA families. This shows that the families were using ABA for a mean of around 21 hours per week, with most employing additional therapists.

[Table 2 about here]

*Post-ABA and Post-ABA control group.* Again, the majority of parental respondents in these groups were mothers ( $N = 24$  (92%) and  $25$  (96%) out of  $26$  respectively). In the Post-ABA group  $24$  respondents were white British,  $1$  was Asian or Asian British and data were missing for  $1$  respondent. In the post-ABA control group all respondents were white British. Parents reported on full biological siblings in all cases. There were no significant group differences in any of the demographic characteristics listed in Table 1.

Fourteen siblings from each group were old enough to complete questionnaires themselves. Due to the small numbers, these data were not separately analyzed. However, they were included in whole group level analysis exploring the differences between sibling, parent and teacher responses (see Results).

Teachers for 65% of the siblings (Post-ABA =  $17$ ; Control =  $17$ ) completed questionnaire measures. Families for whom teacher data were provided did not differ from families for whom such data were not provided in terms of: the age and autism quotient of the

child with autism, the presence of intellectual disabilities in the child with autism, or the gender of the typically developing sibling. However, siblings were significantly younger in families for whom teacher data were obtained ( $t(50) = 3.59, p = .001$ ). Comparison of the Post-ABA and the Control families with a teacher participant revealed no significant between-group differences in any of the demographic variables listed above.

Information on intervention use was available for 22 of the 26 post-ABA families. These families had used ABA for a median of 31.50 months (range from 9 – 96) with a median intensity of 28.50 hours per week (7 – 40). The median age of the children with autism at outset was 3.08 years (1.58 – 5.00) and of siblings was 4.92 years (0.5 – 7.33). The median time since the intervention had last been used was 18 months (1 – 72). Initial phonecalls to participating families indicated that due to the length of time since intervention use, and the fluctuations in use over the course of the program, parents in the post-ABA group inevitably found it more difficult than the ABA group to recall and provide precise figures relating to intervention information.

### *Measures*

Parents were asked to complete six measures covering family demographics, severity of their child's autism, level of parenting stress, family support networks, sibling behavioral adjustment, sibling relationship quality and, for the ABA group, an additional measure of the perceived impact of ABA intervention involvement on the family. Siblings were asked to complete four measures covering behavioral adjustment, sibling relationship quality, social support, plus, for the ABA group, an additional measure of intervention impact. Teachers were asked to complete one measure, a sibling behavioral adjustment questionnaire.

Measures completed by all participants (parents, siblings aged 9-16 years, and teachers):

*Strengths and Difficulties Questionnaire* (SDQ: Goodman, 1997; Goodman, Meltzer, & Bailey, 1998). The SDQ is a 25-item behavioral screening questionnaire covering five domains: conduct problems, emotional symptoms, hyperactivity, peer relationships and pro-social behavior. Each item is rated on a 3-point scale according to how true it is of the child. In addition to individual domain scores, all domains with the exception of the last one can be summed to produce a Total Difficulties score. The parent, teacher and self-report forms contain the same 25 items and all three forms correlate well with other established measures of child behavioral adjustment (Goodman, 1997; Goodman & Scott, 1999; Muris, Meesters, Eijkelenboom & Vincken, 2004). Reported alpha coefficients for the parent, teacher and self-report forms for the Total Difficulties scale are 0.80 or above and for the Prosocial behavior domain are 0.65 or above (Goodman, 2001). Although the self-report form was originally designed for 11-16 year olds, it has been used with children as young as 8 years; internal reliability is somewhat lower for younger children, but most other psychometric properties are comparable to those obtained with older children (Muris et al., 2004).

Measures completed by parents and 9-16 year old siblings:

*Sibling Inventory of Behavior* (SIB: Schaefer & Edgerton, 1981). This 28-item scale was developed for use with families in which there is a child with a disability. It was used to provide a measure of parents' and siblings' perceptions of the sibling relationship quality, by examining the behavior of the typically developing sibling towards the child with autism. Specific behaviors are rated in terms of frequency of occurrence, from one (never) to five (always). Items are broken into four subscales: involvement (7 items), empathy (6 items), unkindness (9 items), and avoidance (6 items). Alpha coefficients of between 0.77 and 0.85 have been reported for a parent version of this scale, and 0.74 to 0.84 for a child version (Cuskelly & Gunn, 2003).

*Intervention impact questionnaire.* (completed by the ABA group only). This 11-item questionnaire, designed for the present study, examined parents' and siblings' perceptions of their current family situation in comparison with their life prior to the ABA program. There was a specific focus on the potential impact on the typically developing sibling. In the parent-version, parents are asked to rate items such as 'you go out places as a family' on a 5-point scale, from one (much less since beginning ABA) to five (much more since beginning ABA). Other than slight differences in wording, the child version is identical to the parent version of the scale, with the exception that a question on the financial impact on the family is omitted from the child version (see Table 6 for a full list of items).

Measures completed by parents only:

*Demographic questionnaire.* This included questions on: the specific diagnosis of the child with autism; family composition; parental ethnicity, education and employment; household income; and use of any interventions with the child with autism.

*Gilliam Autism Rating Scale* (GARS: Gilliam, 1995). The 56-item GARS is a behavioral checklist designed to determine the presence and severity of autism in children and young people aged 3-22 years. It comprises three 14-item subscales (stereotypical behavior, communication and social interaction) in which behaviors are rated from zero (never observed) to three (frequently observed). An additional 14-item, dichotomously-scored subscale focuses on early developmental disturbances. Standard scores from all four subtests are summed and then converted to an Autism Quotient ( $M = 100$ ,  $SD = 15$ ), with higher scores indicating increased likelihood of autism: an Autism Quotient of 90 or above suggests that the person is "probably autistic" (Gilliam, 1995). The measure has a reported alpha coefficient of 0.96 (Gilliam, 1995). In the present study, a very wide range of GARS scores were found (see Table 1), with the lowest scores indicative of a very low

severity/probability of autism. However, the sensitivity of the GARS has previously been questioned, and the use of a lower cut-off score suggested (Lecavalier, 2005; South et al. 2002). It was included in this study as a measure of symptom severity, and to allow group matching, as opposed to a diagnostic measure. All diagnoses of autism were confirmed with parents. The mean GARS scores for the children with autism in the present study are similar to those reported in previous studies in which this measure has been used (e.g. South et al. 2002).

*Parenting Stress Index Short Form* (PSI: Abidin, 1995). The 36-item PSI is a measure of the stress associated specifically with the role of parenting. It comprises three 12-item scales (parental distress, parent-child dysfunctional interaction and difficult child), which, in the main, consist of statements that are rated on a 5-point scale from ‘strongly agree’ to ‘strongly disagree’. Responses are summed to produce a total score, an indication of overall parenting stress. This has a reported alpha coefficient of 0.91 (Abidin, 1995).

*Family Support Scale* (Dunst, Jenkins & Trivette, 1984; Dunst, Trivette & Hamby, 1994). This 18-item scale is designed to measure the perceived availability and helpfulness of a range of sources of support during the previous 3-6 months. Each item is rated as either ‘not available’ or on a scale from one (not helpful at all) to five (extremely helpful). A ‘perceived helpfulness of available support’ total mean score is calculated by adding ratings of all items and then dividing by the number of sources of support available. The total scale has an alpha coefficient of 0.79 (Dunst et al., 1994). On the basis of McConachie and Waring’s (1997) scoring procedure for this measure, items were also broken into two subscales: formal support (4 items, e.g. social services, health care professionals) and informal support (14 items, e.g. family, friends, and social groups).

Measures completed by 9-16 year old siblings only:



*Piers-Harris Children's Self-Concept Scale 2<sup>nd</sup> ed.* (Piers & Herzberg, 2002). This 60-item self-report questionnaire measures how children describe and evaluate their own behavior and attributes. Items are rated as true or false, with these contributing to six domain scores (behavioral adjustment, intellectual and school status, physical appearance and attributes, freedom from anxiety, popularity, and happiness and satisfaction). Scores are also summed to produce a total self-concept score, with higher scores indicating higher levels of self-concept. Piers and Herzberg (2002) reported an alpha coefficient of 0.91 for the total scale.

*Social Support Scale for Children* (Harter, 1985). This 24-item self-report scale was designed to measure children's perceptions of social support received from four sources: parents, teachers, classmates and close friends. Each of the four subscales contains six items, with subscale scores ranging from 6 to 24 and total score from 24 to 96; higher scores indicate higher levels of perceived support. Reported alpha coefficients for the subscales range from 0.72 to 0.88 (Harter, 1985).

### *Procedure*

ABA and control families were recruited through 12 local and national autism support organizations, both general and ABA-specific. Ten of these organizations sent project information and consent packs out to their members, a further two included information about the research in their newsletters. Altogether around 1200 project packs were sent out. Packs were often sent to families on generic mailing lists, and many would have been received by families who did not meet the study inclusion criteria (at least one child in the family on the autism spectrum, and at least one typically developing sibling aged 4 – 16 years). An accurate response rate cannot, therefore, be calculated. After parental and child consent were received (via mail in a postage-paid envelope supplied with the consent forms),

families were phoned and parents asked basic demographic information to ensure that the family met study inclusion criteria.

Questionnaire packs were then posted separately to parents and to participating siblings. Parents were encouraged to look through the sibling pack with their child when it first arrived to ensure that the child understood the instructions, but were then asked to allow the sibling to complete and return the pack independently. Siblings were also encouraged to phone the researcher if they had any queries about completion of the questionnaires. Following the return of the questionnaire packs, participants were sent a letter (with a gift token for the sibling of £5/approx 8 USD) thanking them for their participation. Where family consent to contact the siblings' school was given, an information sheet about the research was sent to the head teacher who was then asked to pass a questionnaire pack on to the class teacher, if they wished to participate. Given the potentially sensitive nature of the research, teachers were asked to regard the questionnaires as confidential.

## Results

### *ABA and ABA Control Group*

*Sibling adjustment.* To assess whether sibling behavioral adjustment in the ABA group differed from that of the ABA control group, SDQ data from the groups were compared using a series of t-tests (Table 3). No significant group differences were found in the parent, sibling or teacher data, either in total score or in any of the domain scores (corrections for multiple comparisons were not applied as results were non-significant). Analysis of the parent data showed that the proportion of the ABA and ABA control group with scores in the “abnormal” range (11% and 9% respectively) was very similar to the proportion of 10% found in community samples (Goodman, 1997).

[Table 3 about here]

To assess whether perceptions of sibling relationship quality in the ABA group differed from that in the ABA control group, SIB data from the groups were then compared using t-tests (Table 4). Again, this revealed no significant group differences in either the parent or the sibling data on any of the domains: empathy, involvement, unkindness or avoidance. ABA parents did rate siblings as showing slightly more kindness towards the child with autism than did control group parents, but this did not reach significance ( $t(88) = -1.76, p = .08$ ).

[Table 4 about here]

Finally, to assess whether sibling self-concept in the ABA group differed from that in the ABA control group, Piers-Harris Self-Concept Scale data were compared using t-tests. Mean self-concept scores were similar in the ABA group and in the ABA control group ( $M = 54.23, SD = 10.81$  and  $M = 51.14, SD = 10.46$  respectively). This difference was non-significant, as were group differences in all domain scores. An identical proportion of each group (91%) had total self-concept scores in the average to high ranges (Piers & Herzberg, 2002).

*Parenting stress and social support measures.* Table 5 shows the parenting stress and social support scores for the ABA and ABA control group. Total parenting stress scores (PSI) were slightly lower in the ABA group than in the ABA control group, but not significantly so. In terms of social support, analysis of the Family Support Scale, using a series of t-tests with a Bonferroni correction of  $p < .01$ , revealed that parents in the ABA group had significantly more sources of formal support available to them than the ABA control group ( $t(88) = 4.02, p < .001$ ). However, there were no significant group differences in terms of the perceived helpfulness of the formal or informal social support available. Analysis of the Social Support Scale for Children completed by the siblings likewise revealed no group differences in perceived social support available from parents, teachers, classmates and close

friends, with perceived levels of total support high in both groups (ABA:  $M = 79.68$ ,  $SD = 10.82$ ; ABA controls:  $M = 80.05$ ,  $SD = 10.15$ ).

[Table 5 about here]

*Intervention impact questionnaire.* Table 6 shows ABA group parent and sibling data on the intervention impact questionnaire. One-sample t-tests with a Bonferroni correction of  $p < .005$  were used to assess whether parents reported significant changes in family life since the intervention had begun (i.e. parent scores for each item were compared to a ‘no change’ score of 3). ABA parents reported significant decreases in the amount of time available for the siblings to spend together, significant decreases in the amount of negative interaction between the siblings, and significant decreases in the finances available to spend on the family, aside from the child with autism. Parents reported significant increases in positive interactions between siblings and significant increases in the number of visitors to the house in connection with the child with autism. No significant changes were reported in any of the other items. A set of one-sample t-tests with a Bonferroni correction of  $p < .005$  were also used to assess whether siblings reported significant changes in family life since the intervention had begun. Siblings reported significant increases in positive interactions with their siblings and significant increases in number of visitors to the house since the ABA program had begun. No other significant changes were reported in any of the other items, although the sibling-reported increase in the time available for them to spend with the child with autism and the reported decrease in negative sibling interactions (both  $p < .05$ ) approached the significance level set.

Parent and sibling data were then compared using paired t-tests with a Bonferroni correction of  $p < .005$ , including only families in which both the parent and child had completed the intervention impact scale. No significant differences were found between the

views of parents and those of siblings on the impact of intervention. However, a number of comparisons neared the significance level set: parents perceived a decrease and siblings an increase in the time available for the sibling to spend with the child with autism since beginning ABA ( $t(19) = -2.50, p = .022$ ); views on negative sibling interaction also diverged somewhat, with parents perceiving somewhat more of a decrease in this than siblings ( $t(18) = -2.17, p = .044$ ); the number of visitors to the house was also an issue where views differed somewhat, with parents perceiving more of an increase in this than siblings ( $t(19) = 2.60, p = .018$ ).

[Table 6 about here]

*Relationships between sibling adjustment, ABA intervention variables, parenting stress and social support in the ABA group.* To explore whether there were any significant relationships between sibling adjustment levels (parent, sibling and teacher SDQ total difficulties and pro-social behavior scores, parent and sibling SIB domain scores, and Piers-Harris total self concept score) and ABA intervention variables (duration, hours per week, mother's hours per week, number of therapists, therapist hours per week, age of child and sibling at outset of intervention, and perceived efficacy), a series of bivariate correlations were conducted within the ABA group. Due to the large number of analyses conducted, a minimum significance level of  $p < .01$  was employed, to minimize the possibility of false positive results. No significant correlations were found, although there was a trend for siblings to rate themselves as higher on SDQ pro-social behavior when there were more therapists working on the ABA intervention ( $r(22) = 0.43, p = .043$ ). There was also a trend for teachers to rate siblings as higher on total difficulties when they came from families who had been using their ABA intervention for a shorter length of time ( $r(29) = -0.37, p = .046$ ).

To explore whether there was any relationship between sibling adjustment levels and parenting stress (PSI), bivariate correlations were conducted in the ABA group, again with

minimum significance levels set at  $p < .01$ . This revealed no significant correlations.

Supplementary analysis showed that parents who perceived their ABA program to be more effective reported lower levels of parenting stress ( $r(45) = -0.429, p = .003$ ).

Parental social support was related to sibling adjustment in the ABA group. The higher the perceived helpfulness of formal support received by parents, the lower the sibling's self-reported SDQ total difficulties score ( $r(22) = -0.54, p = .01$ ). Likewise, the higher the perceived helpfulness of the informal support received by parents, the lower the sibling's self-reported SIB unkindness domain score ( $r(22) = -0.58, p = .004$ ) and the lower the parent-reported SDQ total difficulties score ( $r(22) = -0.42, p = .004$ ). Social support received by siblings was also related to adjustment: siblings who reported higher levels of social support had higher levels of self-concept ( $r(22) = 0.57, p = .006$ ). Similar associations between child social support and self-concept were also found in the ABA control group, although significant associations between parent social support and sibling adjustment did not emerge in this group.

Further exploratory analysis also showed that while autism severity in the child with autism (GARS measure) was related to parental stress levels in the ABA group ( $r(45) = 0.60, p < .001$ ), this was not the case in the control group ( $r(45) = 0.26, ns$ ). Nor was it related to sibling behavioral adjustment, self-concept or relationship quality in either of the groups.

#### *Post-ABA and Post-ABA Control Groups*

*Sibling adjustment.* Longer-term effects of ABA family involvement were assessed by comparison of the parent data for the post-ABA and post-ABA control groups (Table 7). Firstly, parent SDQ data were compared using a series of t-tests. The mean total difficulties scores in the post-ABA group and the post-ABA control group were not significantly

different. This was also the case with the domain scores and the mean pro-social behavior scores. Analysis of teacher SDQ data also revealed no significant group differences.

To assess whether sibling relationship quality in the post-ABA group differed from that in the post-ABA control group, parent SIB data was then compared using t-tests. Again, this revealed no significant group differences for any of the domains.

*Parenting stress measure.* Total parenting stress scores (PSI) in the post-ABA group and the post-ABA control group did not significantly differ (Table 7).

[Table 7 about here]

*Relationships between sibling adjustment and ABA intervention variables in the post-ABA group.* To explore whether there were any significant relationships between sibling adjustment levels (parent SDQ total difficulties and pro-social behavior scores, and parent SIB domain scores) and ABA intervention variables (duration, average intensity, time since intervention last used and age of child and sibling at outset of intervention), a series of bivariate correlations were conducted in the post-ABA group (based on the 22 respondents for whom these data were available), with significance levels again set at  $p = .01$ . No significant relationships were found, with the exception that the older the child with autism had been at the outset of therapy, the higher the parent-reported SDQ total difficulties score for the sibling ( $r(21) = 0.62, p = .003$ ).

#### *Comparison of Parent, Sibling and Teacher Data*

To explore the extent to which parents, siblings and teachers had similar perceptions of sibling adjustment, a series of one-way ANOVAs with a Bonferroni correction of  $p < .008$  were used to compare SDQ data from these three sources. Given the lack of differences found between the groups, data were collapsed for this analysis, which included only families for whom parent, sibling and teacher data were available ( $n = 38$ ). This included some sibling

data from the post-ABA and post-ABA control families not previously analysed. These analyses showed significant group differences in the conduct problems domain ( $F(2,111) = 5.45, p = .006, \eta_p^2 = .089$ ) and in the hyperactivity domain ( $F(2,111) = 5.93, p = .004, \eta_p^2 = .097$ ). Teachers rated siblings as significantly lower on conduct problems than the siblings themselves did ( $M = 0.63, SD = 1.46$  and  $M = 1.74, SD = 1.37$  respectively), although teacher and sibling ratings did not differ significantly from those of parents ( $M = 1.34, SD = 1.60$ ). Teachers rated siblings as significantly lower on the hyperactivity domain than their parents did ( $M = 2.18, SD = 2.77$  and  $M = 3.68, SD = 2.83$  respectively), with these ratings in turn significantly lower than the siblings' own ratings of their behavior in this area ( $M = 4.16, SD = 2.18$ ).

To compare perceptions of sibling relationship quality, the parent and sibling SIB data were also compared using a series of t-tests with a Bonferroni correction of  $p < .01$ , again with group data collapsed, and including all cases where both parent and sibling data were available ( $N = 70$ ). This revealed no significant differences, although siblings did rate themselves as somewhat higher on empathy than did the parents ( $t(138) = -2.35, p = .02$ ).

## Discussion

The present study is part of a small but growing body of literature on the family-wide impact of interventions for autism. It was hypothesized that ABA involvement for children with autism would have a beneficial effect on their siblings in terms of their psychosocial adjustment and their relationship with the child with autism. This hypothesis was not strongly supported, with information gathered from the parents, the siblings and their teachers indicating that the ABA group siblings did not obtain significantly higher scores in comparison to the control group siblings on measures of behavioral adjustment, self-concept



or the quality of their relationship with the child with autism. However, some support for the hypothesis came from the findings from the study-specific intervention impact questionnaire, which revealed significant parent- and sibling- reported increases in positive interactions between the sibling and the child with autism, and significant parent-reported decreases in negative interactions between them since the outset of the intervention. When taking a longer-term view of the impact of intervention involvement on siblings in families who had previously used ABA, but were no longer doing so, findings again showed no significant benefits to siblings in terms of behavioral adjustment and sibling relationship quality.

It is perhaps surprising that the ABA intervention for the children with autism did not translate into substantial benefits for the siblings, particularly when parents on the whole perceived it to be an effective approach for their child: it might have been expected that any improvements in the symptomatology of the child with autism associated with the intervention, would have resulted in more positive interactions within the family, in turn leading to an improved relationship with the sibling. However, it is important to note that, while there were relatively few (albeit perhaps important) significant benefits for the typically developing siblings, there were no significant detrimental effects for their adjustment or sibling relationships either. This was the case both during and following the families' involvement in ABA intervention. The difficulties that were reported by parents (less time for siblings to spend together, decreases in finances available to spend on the family) were not unexpected, and did not have any demonstrable impact on sibling adjustment. In addition, parents and siblings reported no change in the amount of time mothers and fathers had available to spend with the typically developing siblings, the opportunities for family outings, or the time available for siblings to spend with friends since the outset of intervention. These findings are encouraging, in providing no evidence that the use of ABA by families was detrimental for siblings. Overall, the picture that emerged was of

a largely neutral effect on siblings' lives. These findings are very much in line with the few previous studies in this field (Grindle et al., 2009; Hastings 2003b): these also reported an overall picture of mixed or neutral sibling outcomes, but included some positive outcomes for siblings from the parents' perspective. It also builds on these studies by confirming that this picture also holds when the sibling and teachers' perspectives are included.

There are a number of possible explanations for the lack of support for the hypothesis and for these predominantly neutral findings. Firstly, it may be that any potential ABA-specific benefits to the siblings resulting from family ABA involvement are balanced by drawbacks, non-specific to ABA (such as the financial stress associated with all kinds of intervention) to produce a neutral effect overall. Certainly, parents did report both family benefits (e.g. increases in positive sibling interactions) and difficulties (e.g. impact on family finances). This echoes previous research into families using home-based interventions which has reported drawbacks such as disruption to family life, a loss of privacy associated with the use of therapists, and concerns over finances in addition to benefits such as social support from therapists (Grindle et al., 2009; Hastings & Johnson, 2001; Johnson & Hastings, 2002; Williams & Wishart, 2003). It is possible that some of these benefits and drawbacks continue beyond the cessation of the intervention, resulting in neutral outcomes for siblings in families no longer using the program.

Secondly, it may be the case that the ABA siblings in this study were relatively well adjusted, with good sibling relationships, prior to the family's intervention involvement, and it would therefore be unrealistic to expect significant improvements as a result of ABA. Indeed, developmental difficulties in the child with autism prior to intervention may have presented no barrier to the development of a warm and loving sibling relationship. Although sibling adjustment was not measured prior to intervention use in the present study, it was found that siblings' behavioral adjustment scores during the intervention were similar to

those found in community samples, and that a large proportion of siblings had self-concept scores in the average to high range. This does seem to fit with the body of research showing that siblings of children with autism are well adjusted on the whole (e.g. Kaminsky & Dewey, 2002; Pilowsky et al., 2004). Under these circumstances, neutral effects may be expected.

Thirdly, it could be the case that family ABA involvement is beneficial for some siblings, but detrimental for others, and that this individual variation combined to produce an overall picture of neutral effects in the present study. Certainly there was much variation in sibling scores on the various measures. For families considering using this approach it will be important to find better ways of identifying which siblings are likely to cope well and which are likely to experience difficulties during intervention use. As the correlation analysis from the present study shows, such predictions may be difficult to make, as outcome does not seem to relate to patterns of intervention use in any obvious ways. Families naturally wish to implement their intervention to best suit the needs of the whole family (e.g. Williams, 2006), though, so it is important to continue to try to identify factors which contribute to the best outcomes for siblings. The present study shows that one such factor is social support for siblings, and having this in place prior to the outset of intervention may aid sibling adjustment.

Finally, it could also be the case that these findings relate to the particular sample of families who participated in this research. The majority of siblings in this study were older than the child with autism, the children with autism had GARS scores indicative of a relatively low severity of autism overall, and families had already been using ABA for around 3 years, with an intensity of around 20 hours per week, and with additional therapists providing the majority of these hours. The possibility of less positive findings with younger siblings and with families just beginning the intervention and using it more intensively cannot

be ruled out (although it is notable that the present study found no correlation between sibling adjustment and either duration or intensity of use). In addition, it cannot necessarily be concluded that ABA use has no impact at all on siblings, as it is possible that there are more subtle benefits and difficulties that were not picked up by the standardized measures used here.

Findings also showed that parenting stress was no greater in families using ABA than in control families, an encouraging finding given that parenting stress has the potential to influence not only family functioning, but also the effectiveness of interventions for the child with autism (Hastings & Symes, 2002; Osborne, McHugh, Saunders, & Reed, 2008). Parental stress levels were associated with perceived intervention efficacy, something that has also been reported in previous research (Hastings & Johnson, 2001). However no relationship was found between parenting stress and levels of sibling adjustment. This was surprising given that previous studies have reported an association between parent and sibling well-being in families of children with pervasive developmental disorder (e.g. Fisman et al., 2000). Within the present study there were also few relationships found overall between sibling adjustment levels and ABA intervention variables. This was also found to be the case in previous research into sibling adjustment to ABA (Hastings, 2003b). The lack of significant relationships in the present study may relate partly to the fact that many of the siblings in this study were teenagers. Adolescents tend to spend less time with their parents and more time away from the home with friends (Smentana, Campione-Barr, & Metzger, 2006). Such patterns of socializing may have provided participants from the present study with valuable social support, as well as resulting in them being less affected than a younger sample would have been by variations in parenting stress and intervention use. The lack of significant relationships might also relate to the fact that the siblings completed the measures

themselves, preventing any spurious findings of relations between parenting stress and sibling adjustment as a result of the mother completing both measures.

Social support for siblings was found to be of clear importance, and in both the ABA and the control group it was positively associated with self-concept. Although there has been much variation in sibling research findings to date, social support has consistently been shown to be beneficial (Hastings, 2003b; Rivers & Stoneman, 2003). There is now a need to better understand the processes by which this operates, in particular why some siblings are better able to access and benefit from social support than others, and how social support enables siblings to adapt effectively to life with a child with autism in the family.

There were differences in the way in which the ABA and control families used social support. ABA parents had access to a significantly greater number of sources of formal social support than the control group, and parental social support was related to better sibling adjustment in the ABA group, but this was not the case in the control group. These findings suggest that ABA families use somewhat different strategies than other families to manage life with a child with autism. This supports previous research showing that mothers of children with autism who plan to use ABA have different coping styles to mothers of older children with autism not involved in intensive intervention (Hastings et al., 2005). The extent to which the social support and coping strategies adopted by parents then influences those adopted by siblings is unclear, though, in ABA families specifically and in families with children with autism more broadly. To date very few studies have explored sibling coping strategies (Roeyers & Mycke, 1995; Ross & Cuskelly, 2006; Seltzer, Orsmond, & Esbensen, 2009), but these may be an important component in understanding variability in sibling adjustment and in finding ways to improve adjustment in those siblings who do experience difficulties (Cuskelly, 1999).

One of the strengths of the present study was that information was gathered from three linked sources: siblings, parents and teachers. This minimizes the risk of unitary-rater bias, often associated with family research (Rivers & Stoneman, 2003), and increases confidence in the findings. Comparison of responses showed that siblings perceived themselves significantly more negatively than did their parents or their teachers on two of the five SDQ domains. In terms of the quality of the relationship between the sibling and the child with autism, siblings and parents had similar views, although siblings did rate themselves as slightly higher on empathy than their parents did. Rivers and Stoneman (2003) reported similar findings on sibling relationships. They suggested that parents may be less aware of positive sibling interactions because it is the difficulties which come to their attention more often.

It is notable that parents in the ABA group had a somewhat more positive view of the sibling interactions following the use of ABA than the siblings themselves did. Although siblings did report improved interactions with the child with autism, it is possible that ABA may not be quite as beneficial in this area as parents believe, and may still be a source of concern for some siblings. Observational research focusing directly on the interactions between siblings before, during and after the implementation of ABA programs, would be of clear benefit here. Naturalistic research on sibling interactions in families with a child with autism has been conducted (e.g. Knott, Lewis & Williams, 2007) but little, if any, such research has been undertaken specifically with families using home-based interventions. Such work would be invaluable, particularly if linked to complementary information from the standardized measures that are more typically used in evaluation research. It would also allow for exploration of the extent to which siblings informally learn and implement the intervention techniques that their parents are using (see Grindle et al., 2009), and the impact of this on sibling communication, interactions and relationship quality.

In the future, longitudinal research would be helpful in better understanding whether sibling adjustment varies over the course of intervention use. Although in the present study sibling adjustment was not found to relate directly to intervention duration or intensity, it may nevertheless fluctuate over time. For example, sibling adjustment may be more affected at the outset of intervention while the family adapts to new experiences and routines. Longitudinal research would also be helpful because it would enable matching of ABA and control families prior to the outset of intervention. This would mean that any changes in sibling adjustment resulting from improvements in the symptomatology or behavior of the child with autism would not be missed as a result of group-matching on these variables after the intervention had already been in use for some time. Although analysis in the present study suggested that sibling adjustment was not significantly associated with symptomatology of the child with autism, a longitudinal design would nevertheless allow further investigation of how the child with autism and the sibling develop over time, and how their development and adjustment are interlinked. It would also be helpful to include comparison groups of siblings from families using other types of intervention approach with their child with autism. This would mean that families considering intervention use would then be able to access information about the potential impact on siblings associated with different approaches.

There are a number of methodological points to bear in mind when considering the findings of the present study. As with any family research, parents suffering high levels of stress would be unlikely to have volunteered to participate in the study, and the 132 families who did participate may therefore not have been fully representative of all families with a child on the autism spectrum. It should also be noted that ABA parents and siblings were asked to compare their family situation during the intervention with that prior to the start of their ABA program. For some families this covered a period of three or more years, raising the possibility that changes during this period resulted from factors other than ABA use. In

future research it would also be useful to gather information on intervention funding, as it is possible that family stress differs according to whether families self-fund and/or how difficult it is for them to source funding. Lastly, no measure of autism symptomatology was gathered in relation to the siblings themselves. Although siblings were excluded if they had a diagnosis on the autism spectrum, it is possible that some siblings in both the ABA and control groups had more subtle autistic symptoms (broader autism phenotype). Such genetic effects have been shown to be associated with sibling outcome, particularly in the presence of a high number of stressful life events (Orsmond & Seltzer, 2009).

A final point worth emphasizing is that the present study was not designed to evaluate the efficacy of ABA itself: the lack of significant effects found therefore has no implication for the existing evidence of the efficacy of this approach. Rather, this study used groups closely matched on a wide range of demographic variables to provide a detailed examination of sibling adjustment in families using ABA. The multi-informant responses showed that while ABA use did not have a strongly beneficial impact on the well-being of siblings neither did it have a detrimental effect. Both parents and siblings felt that interactions between the sibling and the child with autism had improved since the outset of intervention, whilst other factors, such as parental time with the siblings was unchanged. Findings from this study are therefore encouraging, and suggest that ABA intervention use, which may benefit the child with autism, will not necessarily cause sibling adjustment difficulties.



## References

- Abidin, R. R. (1995). *Parenting Stress Index Professional Manual* (3<sup>rd</sup> ed). Lutz, FL.: Psychological Assessment Resources, Inc.
- Bågenholm, A. & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: a population-based study. *Journal of Mental Deficiency Research*, 35, 291-307.
- Birnbrauer, J. S. & Leach, D. J. (1993.) The Murdoch Early Intervention Program after 2 years. *Behaviour Change*, 10, 63–74.
- Cox, M. J., & Paley, B. (1997). Families as systems. *Annual Review of Psychology*, 48, 243-267.
- Cuskelly, M. (1999). Adjustment of siblings of children with a disability: Methodological issues. *International Journal for the Advancement of Counselling*, 21, 111-124.
- Cuskelly, M. & Gunn, P. (2003). Sibling relationships of children with Down syndrome: Perspectives of mothers, fathers and siblings. *American Journal on Mental Retardation*, 108, 234-244.
- Dunst, C. J. Jenkins, V. & Trivette, C. M. (1984). The Family Support Scale: Reliability and validity. *Journal of Individual, Family and Community Wellness*, 1, 45-52.
- Dunst, C. J., Trivette, C. M. & Hamby, D. W. (1994). Measuring social support in families with young children with disabilities. In C. J. Dunst, C. M. Trivette, and A. G. Deal (Eds) *Supporting and Strengthening Families, Vol. 1: Methods, Strategies and Practices*. Cambridge: Brookline Books Inc.
- Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2010) Using participant data to extend the evidence base for intensive behavioural intervention for children with autism. *American Journal on Intellectual and Developmental Disabilities*, 115, 381-405.

- Fisman, S., Wolf, L., Ellison, D., Gillis, B., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *Canadian Journal of Psychiatry*, 45, 369-375.
- Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T. & Szatmari, P. (1996). Risk and protective factors affecting the adjustment of siblings of children with chronic disabilities. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35, 1532-1541.
- Gilliam, J. E. (1995). *Gilliam Autism Rating Scale*. Austin, TX.: Pro-Ed.
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology and Psychiatry*, 38, 581-586.
- Goodman, R. (2001). Psychometric properties of the Strengths and Difficulties Questionnaire. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 1337-1345.
- Goodman, R., Meltzer, H., & Bailey, V. (1998). The Strengths and Difficulties Questionnaire: A pilot study on the validity of the self-report version. *European Child and Adolescent Psychiatry*, 7, 125-130.
- Goodman, R. & Scott, S. (1999). Comparing the Strengths and Difficulties Questionnaire and the Child Behavior Checklist: Is small beautiful? *Journal of Abnormal Child Psychology*, 27, 17-24.
- Grindle, C. F., Kovshoff, H., Hastings, R. P., & Remington, B. (2009). Parents' experiences of home-based applied behavior analysis programs for young children with autism. *Journal of Autism and Developmental Disorders*, 39, 42-56.
- Harter, S. (1985). *Manual for the Social Support Scale for Children*. Denver, CO.: University of Denver.
- Hastings, R. P. (2003a). Brief report: Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 33, 99-104.

- Hastings, R. P. (2003b). Behavioral adjustment of siblings of children with autism engaged in ABA early intervention programs: the moderating role of social support. *Journal of Autism and Developmental Disorders*, 33, 141-150.
- Hastings, R. P. & Johnston, E. (2001). Stress in UK families conducting intensive home-based behavioral interventions for their young child with autism. *Journal of Autism and Developmental Disorders*, 31, 327-336.
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., degli Espinosa, F., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9, 377-391.
- Hastings, R. P. & Symes, M. D. (2002). Early intensive behavioural intervention for children with autism: Parental therapeutic self-efficacy. *Research in Developmental Disabilities*, 23, 332-341.
- Hodapp, R. M., Glidden, L. M. & Kaiser, A. P. (2005). Siblings of persons with disabilities: Toward a research agenda. *Mental Retardation*, 43, 334-338.
- Johnson, E. & Hastings, R. P. (2002). Facilitating factors and barriers to the implementation of intensive home-based behavioural intervention for young children with autism. *Child: Care, Health and Development*, 28, 123-129.
- Kaminsky, L. & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 43, 225-232.
- Knott, F. Lewis, C., & Williams, T. (2007). Sibling interaction of children with autism: Development over 12 months. *Journal of Autism and Developmental Disorders*, 37, 1987-1995.
- Lecavalier, L. (2005). An evaluation of the Gilliam Autism Rating Scale. *Journal of Autism and Developmental Disorders*, 35, 795-805.

- Macks, R. J. & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders*, 37, 1060-1067.
- Mates, T. E. (1990). Siblings of autistic children: Their adjustment and performance at home and school. *Journal of Autism and Developmental Disorders*, 20, 545-553.
- McConachie, H. & Waring, M. (1997). *Child Psychology Portfolio: Parental Coping and Support*. Windsor, UK: NFER-Nelson.
- Muris, P., Meesters, C., Eijkelenboom, A. & Vincken, M. (2004). The self-report version of the strengths and difficulties questionnaire: Its psychometric properties in 8- to 13-year old non-clinical children. *British Journal of Clinical Psychology*, 43, 437-448.
- Orsmond, G. I. & Seltzer, M. M. (2009). Adolescent siblings of individuals with an autism spectrum disorder: Testing a diathesis-stress model of sibling well-being. *Journal of Autism and Developmental Disorders*, 39, 1053-1065.
- Osborne, L. A. McHugh L., Saunders, J. & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 38, 1092-1103.
- Piers, E. V. & Herzberg, D. S. (2002). Piers-Harris Children's Self-Concept Scale (2<sup>nd</sup> ed). Los Angeles, CA.: Western Psychological Services.
- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 45, 855-865.
- Reichow, B. (2011) Overview of meta-analyses on early intensive behavioral intervention for young children with autism spectrum disorders, *Journal of Autism and Developmental Disorders*.
- Remington, B., Hastings, R. P., Kovshoff, H., degli Espinosa, F., Jahr, E., Brown, T., Alsford, P., Lemaic, M., & Ward, N. (2007). Early intensive behavioural intervention:

- Outcomes for children with autism and their parents after two years. *American Journal on Mental Retardation*, 112, 418-438.
- Rivers, J. W. & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33, 383-394.
- Roeyers, H. & Mycke, K. (1995). Siblings of a child with autism, with mental retardation and with a normal development. *Child: Care, Health and Development*, 21, 305-319.
- Ross, P. & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability*, 31, 77-86.
- Schaefer, E. & Edgerton, M. (1981). *The Sibling Inventory of Behaviour*. Unpublished manuscript, University of North Carolina, Chapel Hill.
- Schwichtenberg, A. & Poehlmann, J. (2007). Applied behaviour analysis: Does intervention intensity relate to family stressors and maternal well-being? *Journal of Intellectual Disability Research*, 51, 598-605.
- Seltzer, M. M., Orsmond, G. I., & Esbensen, A. J. (2009). Siblings of individuals with an autism spectrum disorder: Sibling relationships and wellbeing in adolescence and adulthood. *Autism*, 13, 59-80.
- Smentana, J. G., Campione-Barr, N., & Metzger, A. (2006). Adolescent development in interpersonal and societal contexts. *Annual Review of Psychology*, 57, 255-284.
- Smith, T., Groen, A. D., Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, 105, 269-285.
- South, M., Williams, B. J., McMahon, W. M., Owley, T., Filipek, P. A. *et al.* (2002) Utility of the Gilliam Autism Rating Scale in research and clinical populations. *Journal of Autism and Developmental Disorders*, 32, 593 – 599.

- Stoneman, Z. (1998). Research on siblings of children with mental retardation: Contributions of developmental theory and etiology. In J.A. Burack, R.M. Hodapp & E. Zigler (Eds.) *Handbook of Mental Retardation and Development* (pp 669-692). Cambridge: Cambridge University Press.
- Verté, S., Roeyers, H. & Buysse, A. (2003). Behavioural problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health and Development*, 29, 193-205.
- Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6, 115–130.
- Williams, K. R. (2006). The Son-Rise Program intervention for autism: Prerequisites for evaluation. *Autism: The International Journal of Research and Practice*, 10, 86-102.
- Williams, K. R. & Wishart, J. G. (2003). The Son-Rise Program intervention for autism: An investigation into family experiences. *Journal of Intellectual Disability Research*, 47, 291-299.

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Table 1. Demographics characteristics

	ABA (N = 45)	ABA control (N = 45)	Post-ABA (N = 26)	Post-ABA control (N = 26)
<b><i>Child with Autism (reference child)</i></b>				
Age in years – mean (SD)	7.25 (2.33)	7.67 (2.83)	8.92 (2.42)	8.08 (2.25)
Gender: Male	39 (87%)	38 (84%)	22 (85%)	22 (85%)
Female	6 (13%)	7 (16%)	4 (15%)	4 (15%)
Diagnosis:				
Autism	36 (80%)	33 (73%)	23 (88%)	22 (85%)
Other (Asperger's syndrome, ASD, HFA <sup>a</sup> )	9 (20%)	12 (27%)	3 (12%)	4 (15%)
Autism quotient (GARS <sup>b</sup> ) - mean (SD)	88.00 (12.36)	93.00 (12.84)	87.04 (14.04)	92.08 (12.21)
- range	63 - 120	67 - 123	50 - 111	68 - 113
Intellectual disabilities	10 (22%)	14 (31%)	13 (50%)	11 (42%)
Other additional diagnosis <sup>c</sup>	7 (16%)	6 (13%)	4 (15%)	4 (15%)
School/pre-school attendance:				
Full-time	17 (38%)	38 (84%)*	26 (100%)	26 (100%)
Part-time	25 (56%)	3 (7%)	0	0
Does not attend	3 (7%)	4 (9%)	0	0
<b><i>Typically developing sibling</i></b>				
Age in years – mean (SD)	9.08 (2.42)	9.25 (3.25)	9.92 (2.25)	9.67 (3.08)
Gender: Male	21 (47%)	18 (40%)	15 (58%)	14 (54%)
Female	24 (53%)	27 (60%)	11 (42%)	12 (46%)
Older than reference child	38 (84%)	31 (69%)	17 (65%)	18 (69%)
Gender match with reference child	21 (47%)	17 (38%)	15 (58%)	12 (46%)
<b><i>Family</i></b>				
Two-parent/blended two-parent household	41 (91%)	38 (84%)	25 (96%)	23 (89%)
Mother employed	20 (44%)	23 (51%)	16 (62%)	16 (62%)
Partner employed <sup>d</sup>	35 (83%)	38 (93%)	25 (96%)	21 (81%)
Respondent's education <sup>e</sup> – mean (SD)	3.57 (1.37) N=44	3.20 (1.49)	3.20 (1.26) N=25	2.96 (1.69)
Annual household income <sup>f</sup> – mean (SD)	4.07 (2.42) N=43	3.18 (1.87) N=44	3.96 (1.90) N=24	3.24 (1.99) N=25



Children in household – mean (SD)	2.53 (0.76)	2.47 (0.79)	2.42 (0.58)	2.46 (0.81)
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Note:

There were a few comparisons (partner employment in the case of ABA/ABA Controls; diagnosis, number of two-parent households, partner employment in the case of Post-ABA/Post-ABA Controls) where Chi-square analysis could not be performed because cell(s) had an expected value of less than 5. However, as the groups were nearly exactly matched on these variables, statistical comparison was not necessary.

<sup>a</sup> ASD = autism spectrum disorder; HFA = high functioning autism

<sup>b</sup> Gilliam Autism Rating Scale

<sup>c</sup> ABA group :3 = dyspraxia; 1 each of ADHD, hypothyroidism, epilepsy; 1 = Missing data. ABA control group: 1 each of dyspraxia, hypotonia, Cerebral Palsy, epilepsy, Coeliac disease & tuberous sclerosis. Post-ABA group: 2 = dyspraxia; 1 each of anaphylaxis and ADHD. Post-ABA control group: 1 each of dyspraxia, hypotonia, Coeliac disease & tuberous sclerosis.

<sup>d</sup> Calculated as a percentage of applicable families (ABA group = 42; ABA control group = 41; Post-ABA group = 26; Post-ABA control group = 23)

<sup>e</sup> None = 0; GCSE = 1; A levels = 2; College = 3; University degree = 4; Postgraduate = 5

<sup>f</sup> < £10k = 0; £10k - £15k = 1; £15,001 - £30k = 2; £30,001 - £45k = 3; £45,001 - £60k = 4; £60,001 - £75k = 5; £75,001 - £90k = 6; £90,001 - £100k = 7; > £100k = 8

\*  $p < .001$

Table 2. Characteristics of intervention use in ABA Families (N = 45)

Characteristic	Median or Number (%)	Min. – Max.
Duration of use (months)	36.00	2.00 – 96.00
Age of child at outset of intervention (years)	3.71	2.00 – 9.92
Age of sibling at outset of intervention (years)	5.58	1.25 – 10.83
Intensity (hours per week of home use)	18.00	5.00 – 40.00
Mother as therapist on ABA intervention	19 (42%)	
Mother's hours per week on intervention <sup>a</sup>	3.00	1.50 – 40.00
Partner as therapist	8 (18%)	
Partner's hours per week on intervention <sup>a</sup>	3.00	1.50 – 10.00
Families employing additional therapists	40 (89%)	
Therapist hours per week on intervention <sup>a</sup>	20.00	5.00 – 38.00
Intervention management primarily undertaken by:		
Mother/partner	29 (64%)	
Outside agency	8 (18%)	
Parents & outside agency jointly	7 (16%)	
Information missing	1 (2%)	
Characteristic	Mean	Range
Perceived efficacy of intervention <sup>b</sup>	5.82 (1.09)	3.00 – 7.00

<sup>a</sup> Mean hours calculated for those involved as a therapist, not across the whole sample<sup>b</sup> 1 = not at all effective; 7 = very effective

Table 3. Strengths and Difficulties Questionnaire (SDQ) scores - ABA and ABA control group

SDQ Domain	Parent data <sup>a</sup>			Sibling data <sup>b</sup>			Teacher data <sup>c</sup>		
	ABA	ABA control	t (88)	ABA	ABA control	t (42)	ABA	ABA control	t (61)
Emotional problems	2.76 (2.16)	2.44 (2.37)	0.65	3.05 (2.17)	3.50 (2.67)	-0.62	3.00 (2.98)	2.18 (1.96)	1.30
Conduct problems	1.33 (1.87)	1.24 (1.38)	0.26	1.86 (1.28)	1.95 (1.94)	-0.18	0.63 (0.96)	0.52 (1.25)	0.42
Hyperactivity	3.40 (3.09)	3.42 (2.33)	-0.04	4.14 (2.34)	4.05 (2.24)	0.13	3.33 (3.10)	2.36 (2.94)	1.28
Peer problems	1.51 (1.80)	1.42 (1.53)	0.25	2.00 (1.23)	2.82 (2.13)	-1.56	1.80 (1.75)	1.67 (2.10)	0.27
Total score	9.00 (6.59)	8.53 (5.07)	0.38	11.05 (5.02)	12.32 (7.15)	-0.68	8.77 (6.63)	7.00 (5.61)	1.15
Pro-social behaviour	8.27 (1.91)	8.31 (1.81)	-0.11	7.59 (2.21)	8.09 (1.60)	-0.86	7.50 (2.60)	8.18 (2.23)	-1.12

<sup>a</sup> N = 45 per group<sup>b</sup> N = 22 per group<sup>c</sup> ABA group N = 30; Control group N = 33

Table 4. Sibling Inventory of Behaviour (SIB) Scores - ABA and ABA control group

Domain	Parent data <sup>a</sup>			Sibling data <sup>b</sup>		
	ABA	ABA control	t (88)	ABA	ABA control	t (42)
Empathy	23.96 (4.28)	23.33 (4.18)	0.70	26.32 (3.73)	25.05 (5.12)	0.94
Involvement	22.62 (5.20)	22.62 (5.39)	0.00	24.68 (5.82)	22.59 (6.97)	1.08
Unkindness	21.58 (5.79)	23.84 (6.43)	-1.76	20.55 (5.88)	22.05 (8.93)	-0.66
Avoidance	10.29 (3.90)	11.47 (4.69)	-1.30	10.82 (5.50)	12.73 (5.49)	-1.15

Note: Maximum possible scores: Empathy = 30; Involvement = 35; Unkindness = 45; Avoidance = 30

<sup>a</sup> N = 45 per group

<sup>b</sup> N = 22 per group

Table 5. Parenting stress and social support scores – ABA and ABA control group

Measure	ABA	ABA control	t (88)
	Mean (SD)	Mean (SD)	
Parenting Stress Index	101.22 (18.27)	108.39 (20.06)	-1.76
Family Support Scale:			
Sources of formal support <sup>a</sup>	3.47 (0.76)	2.73 (0.96)	4.02 *
Sources of informal support <sup>b</sup>	9.31 (2.59)	10.53 (2.31)	- 2.36
Perceived helpfulness of formal support <sup>c</sup>	2.97 (0.85)	2.86 (1.04)	0.55
Perceived helpfulness of informal support <sup>c</sup>	2.67 (0.64)	2.70 (0.74) <sub>z</sub>	- 0.19

Note: Maximum possible scores: <sup>a</sup> = 4; <sup>b</sup> = 14; <sup>c</sup> = 5

\*  $p < .001$

Table 6. Intervention Impact questionnaire - ABA group

Item	Parent data <sup>a</sup>	Comparison to 'no	Sibling data <sup>b</sup>	Comparison to 'no
	Mean (SD)	change' score t(43)	Mean (SD)	change' score t(19)
Maternal time with sibling	3.34 (1.31)	ns	2.85 (1.09)	ns
Partner time with sibling	3.20 (0.87)	ns	3.25 (1.16)	ns
Siblings' time together	2.34 (0.96)	-4.54**	3.60 (1.19)	2.26
Negative sibling interaction	1.93 (0.97)	-7.14**	2.35 (1.27)	-2.29
Positive sibling interaction	4.14 (0.85)	8.85**	3.95 (1.10)	3.87*
Visitors to house	4.43 (0.85)	11.22**	3.75 (0.97)	3.47*
Space in house for sibling	2.73 (0.90)	ns	2.65 (1.09)	ns
Family outings	3.09 (1.31)	ns	3.40 (1.14)	ns
Sibling involvement in housework	3.12 (0.40)	ns	3.40 (1.05)	ns
Finances available for family	2.18 (1.04)	-5.22**	omitted	omitted
Sibling time with friends	3.16 (0.86)	ns	3.40 (1.27)	ns

\*  $p < .01$ ; \*\*  $p < .001$

Note: Items were rated on a 5-point Likert scale (1 = much less since beginning ABA; 2 = somewhat less; 3 = the same; 4 = somewhat more; 5 = much more).

<sup>a</sup> N = 44

<sup>b</sup> N = 20. There were 22 siblings in the ABA group who were old enough (9 – 16 years) to complete this measure, but two were too young when the ABA intervention began to remember the pre-ABA family situation.

Table 7. Parent Strength and Difficulties Questionnaire (SDQ), Sibling Inventory of Behaviour (SIB), and Parenting Stress Index (PSI) scores - Post-ABA and Post-ABA control group

Measure	Post-ABA (N = 26)	Post-ABA control (N = 26)	t (50)
SDQ Total score	7.69 (4.77)	9.00 (5.34)	- 0.93
SDQ Pro-social behaviour	8.62 (1.27)	8.50 (1.56)	0.29
SIB Empathy	24.23 (5.03)	23.69 (3.81)	0.44
SIB Involvement	22.31 (6.21)	23.38 (5.11)	- 0.68
SIB Unkindness	21.31 (6.40)	23.31 (6.22)	- 1.14
SIB Avoidance	10.88 (4.13)	10.88 (3.10)	0.00
PSI	103.31 (19.95)	103.81 (20.42)	- 0.09

Note: Maximum possible SIB scores: Empathy = 30; Involvement = 35; Unkindness = 45; Avoidance = 30